



Children's Hospital
Informatics Program



Harvard
Medical School

Personally-Controlled Medical Records for Public Health

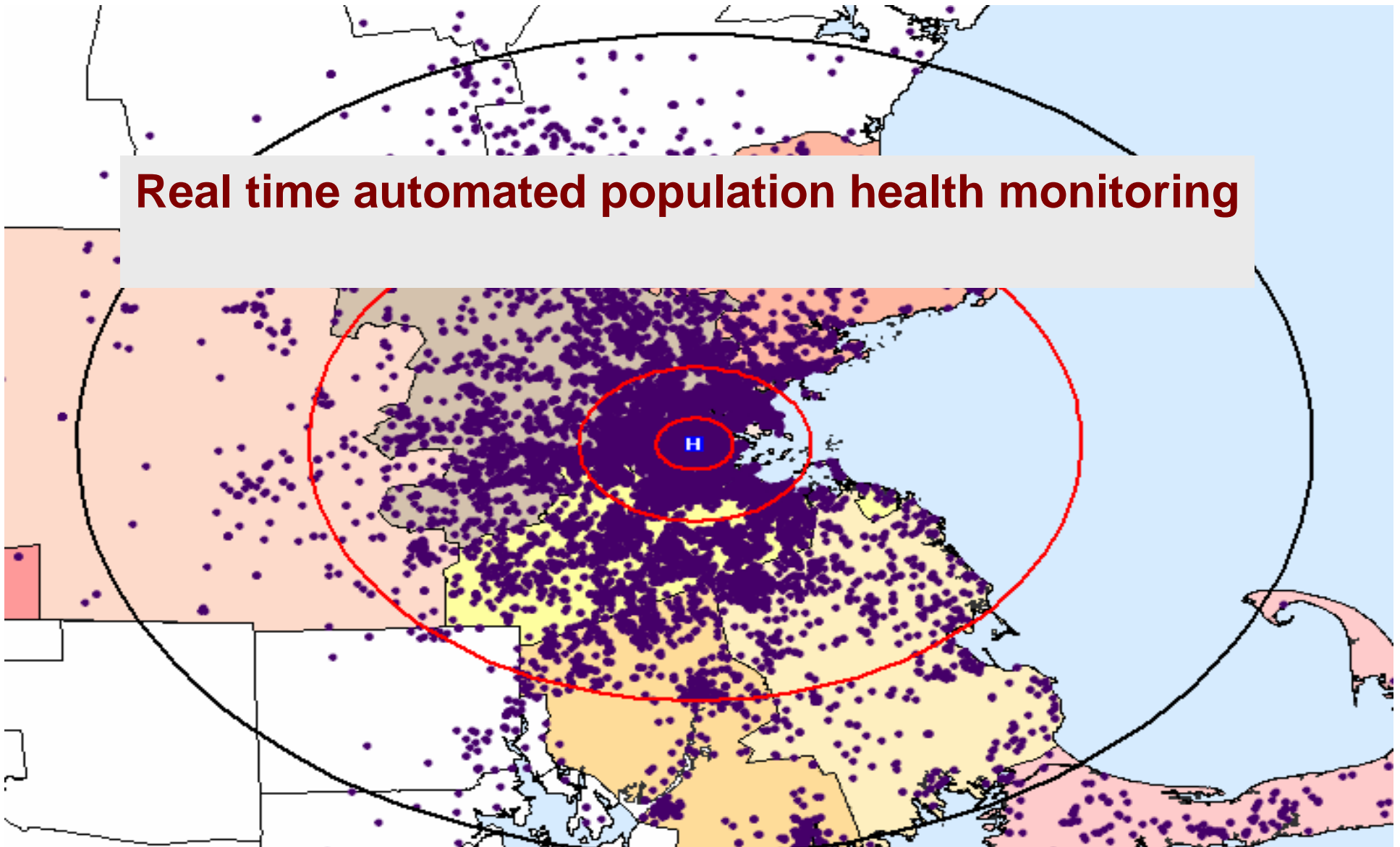
Kenneth D. Mandl, MD, MPH
Informatics Program
Harvard—MIT—Children's Hospital Boston

One motivation

- Raison d'être for a personally controlled health record
 - ✓ Clinical
 - ☞ Personal
 - ☞ Health system
 - ✓ Public health
 - ✓ Quality of care/patient safety
 - ✓ Research

Amuse bouche

Real time automated population health monitoring



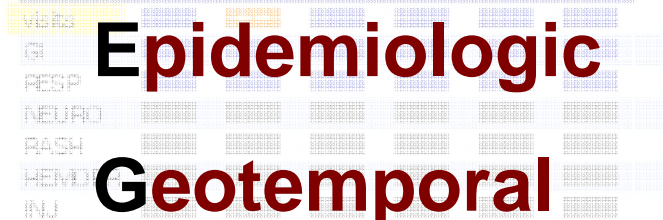
Viewing ALL visits at Children's Hospital Boston for 4/11.

SELECT DATE


☒ March ☐ April

SELECT

ALLMA chib balmc mgh camb somer

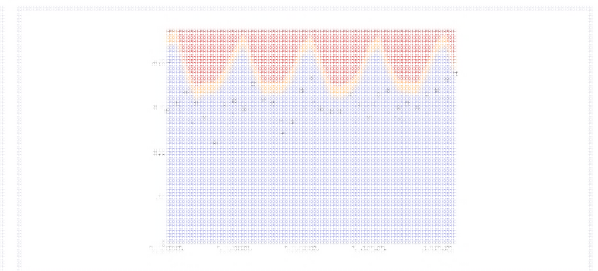
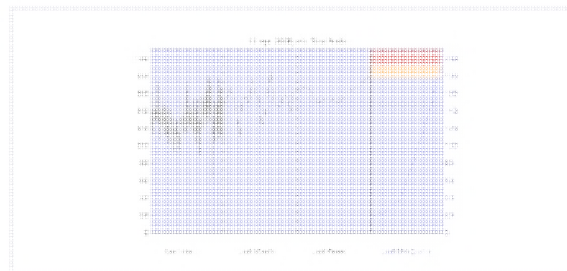
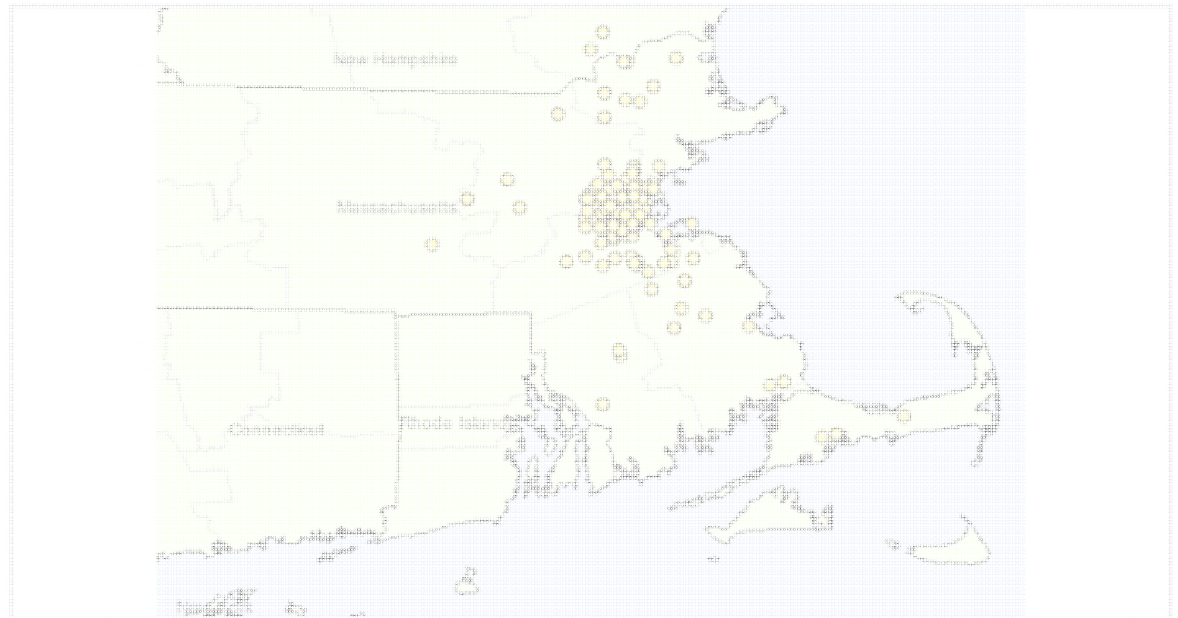


SELECT ALARM



EXPORT

SUMMARY



SYNDROMIC SYMBOLS

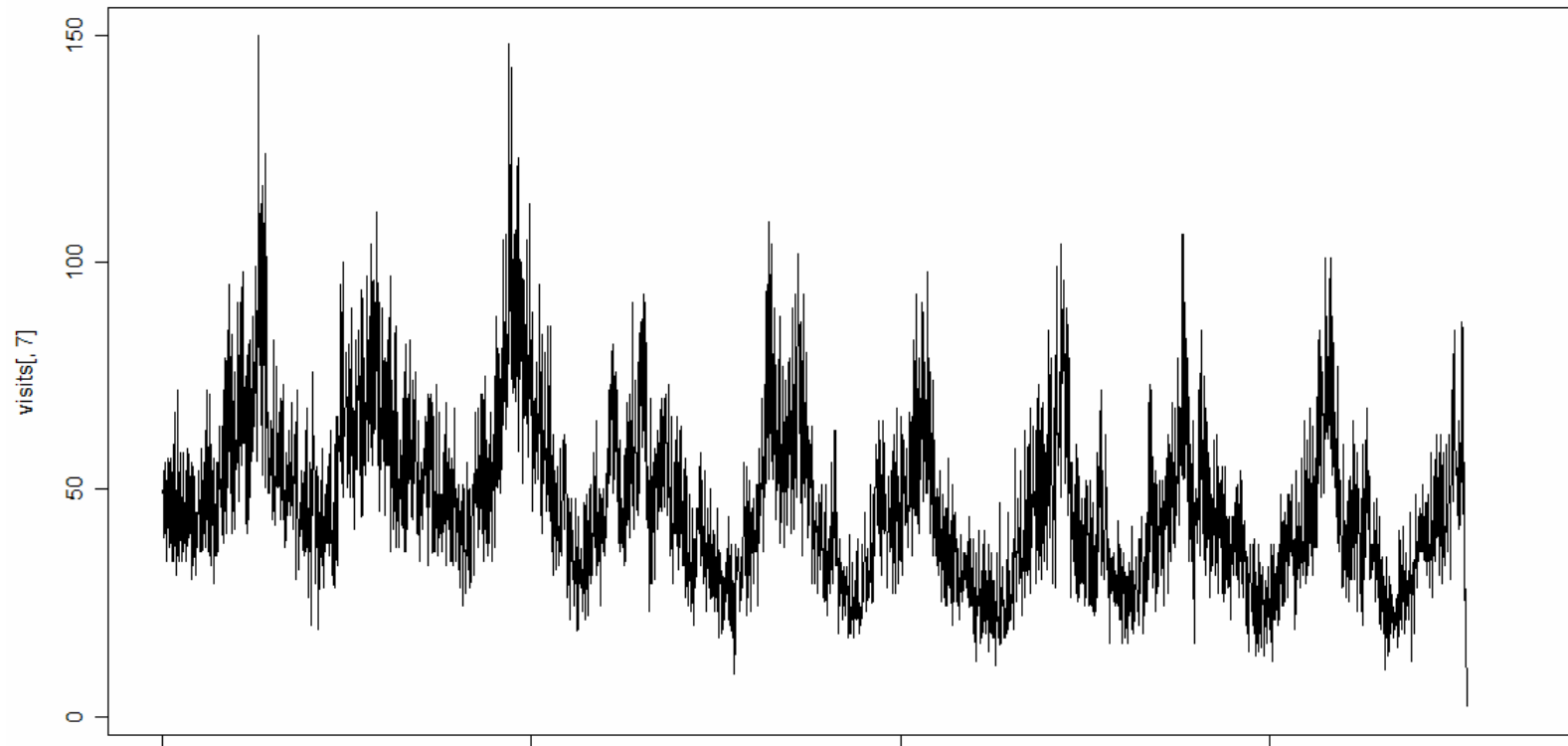
Active Inactive



SYNDROMIC SYMBOLS

Today's alarm level is 1 at Children's Hospital Boston for all visits using the Moving-Average model with ARIMA. The number of visits within this category was 187 and the expected number of visits for today was 148.0224. There is at least a 97% chance that this represents truly abnormal conditions.

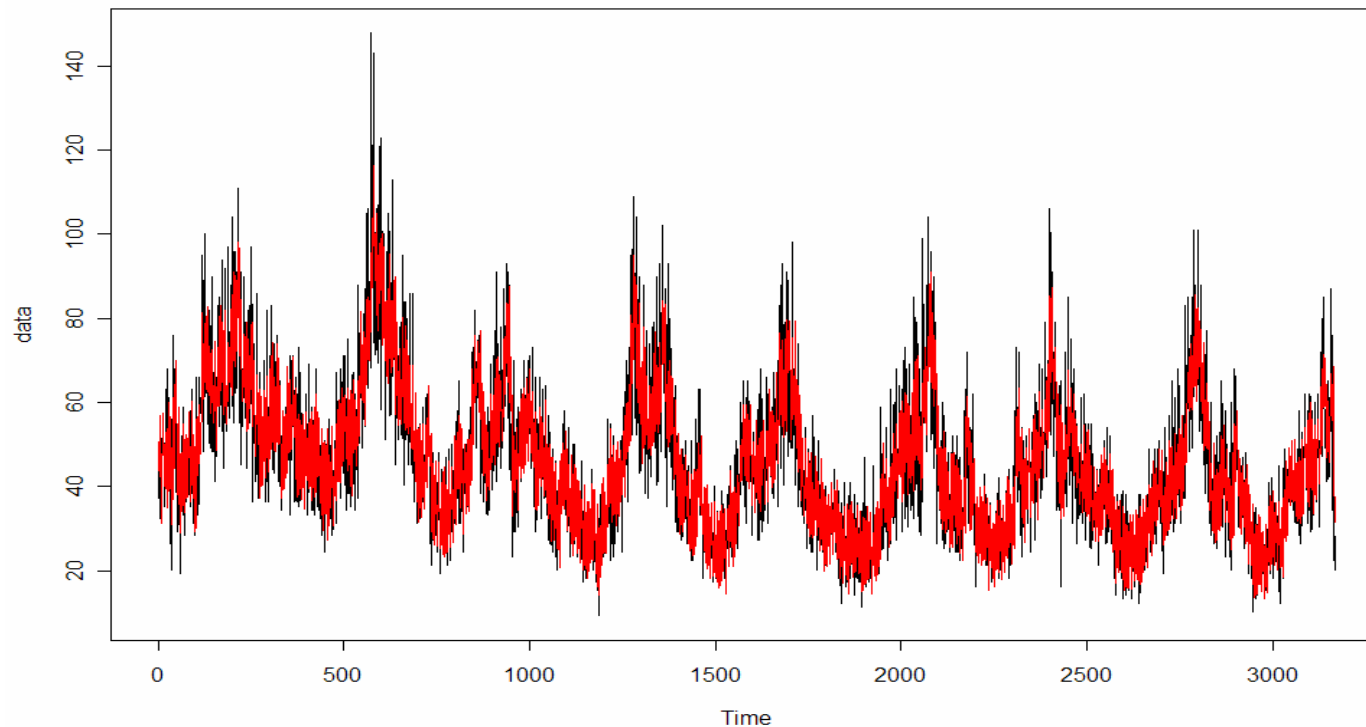
Observed data



Daily counts of ED visits for respiratory syndromes from 1992 to 2002

The model forecast

Modeled data (red) on top of observed data (black)



Reis & Mandl et al, BioMed Central 2003

Value

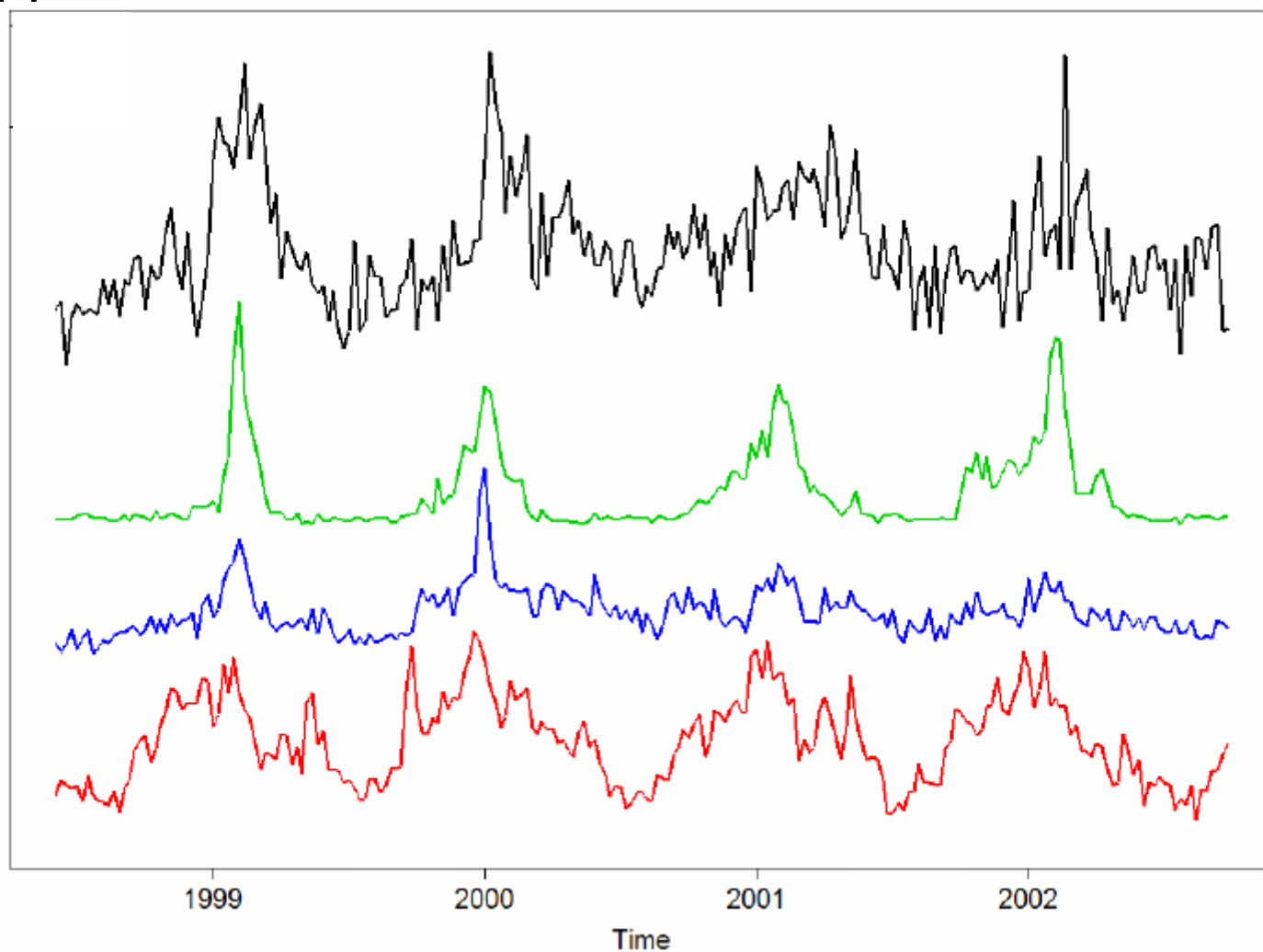
A superior approach to influenza surveillance

**Pneumonia/
Influenza
Mortality
(CDC)**

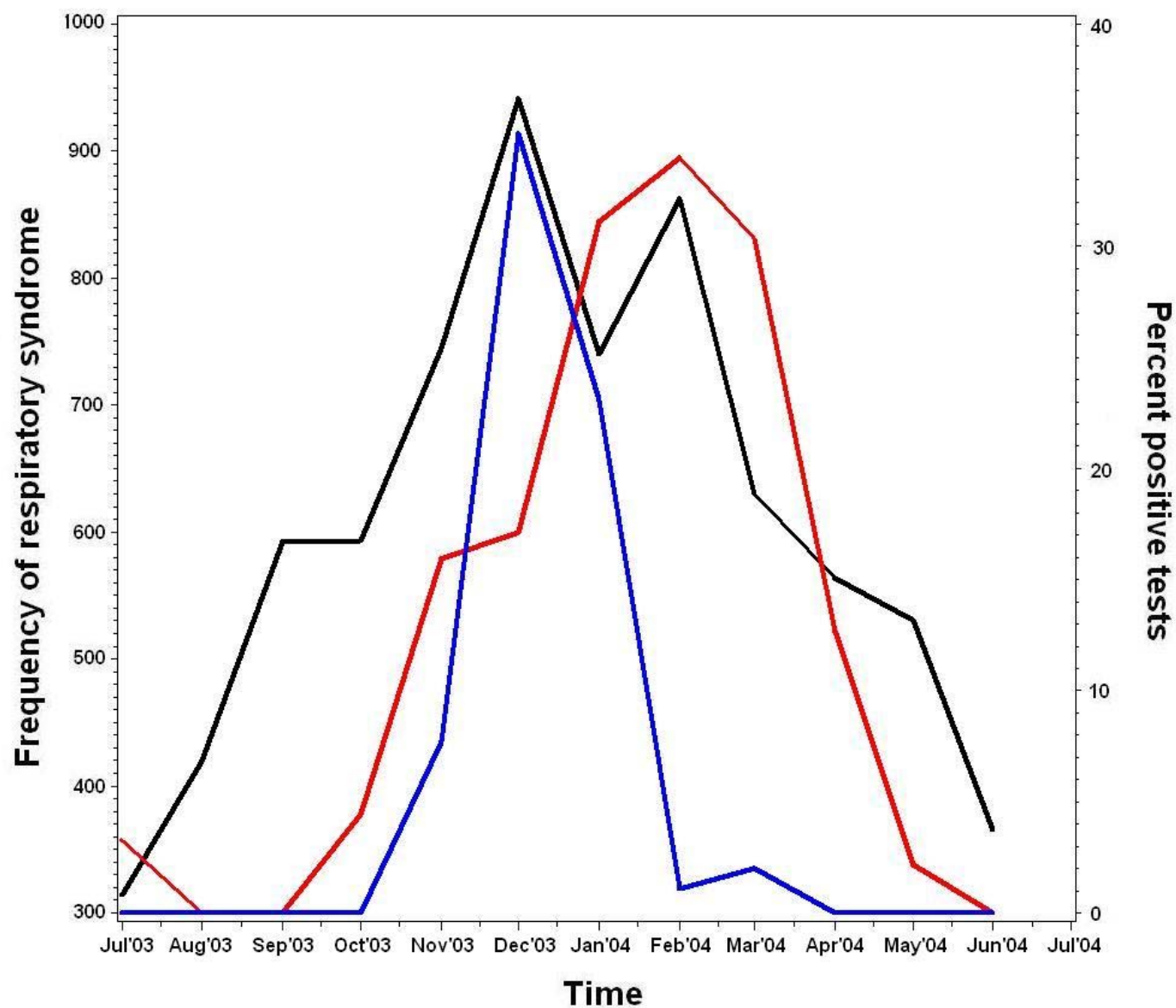
**Influenza
like illness
(CDC)**

Adult ED

Pediatric ED



Biological validation



AEGIS

- Data are automatically and securely sent from emergency departments and clinics, as soon as patients are registered.
- Cases are instantly appended to time series and plotted on maps
- Geotemporal clustering algorithms are applied to the data streams, comparing prevailing conditions with a normal baseline
- When patterns of disease are abnormal, an electronic message is sent to
 - ✓ participating emergency departments
 - ✓ local and state departments of public health



Children's Hospital
Informatics Program



Harvard
Medical School

What is needed

- PHI (personal health information)
- Electronic PHI
- Interpretable electronic PHI
- Standardized interpretable electronic PHI
- Flowing standardized interpretable electronic PHI

What we have generally

- PHI (personal health information) –**lots**
- Electronic PHI –**some**
- Interpretable electronic PHI –**little**
- Standardized interpretable electronic PHI very –**little**
- Flowing standardized interpretable electronic PHI –**tiny**

What we have in AEGIS

- PHI (personal health information) –yes
- Electronic PHI –demographic, diagnostic, laboratory
- Interpretable electronic PHI –much requires text parsing
- Standardized interpretable electronic PHI –HL7, LOINC
- Flowing standardized interpretable electronic PHI –some!

Where can we get more? EHR: the Holy Grail?

- Unified views of citizen records
 - ✓ over time
 - ✓ across institutions
- An emerging data source for
 - ✓ public health activity
 - ✓ population health monitoring
 - ✓ outbreak detection
- managing clinical populations
- measuring process and outcomes in health care
- improving patient safety and healthcare quality

No--Holy Grail not yet found

- The EHR has
 - ✓ not been widely enough deployed
 - ✓ not yielded views of citizen information across institutions and over time
 - ✓ nor been successfully leveraged to advance evidence-based practice
- This, despite
 - ✓ optimistic outlook for the EHR for 30+ years
 - ✓ massive investment in EHR “dot coms”



Children's Hospital
Informatics Program



Harvard
Medical School

**Why is the
EHR not
widely
adopted?**

Standards have been slow to emerge



Britain India/
 Hong Kong Britain
 (Shaver) Europe Australia N. America S. Africa

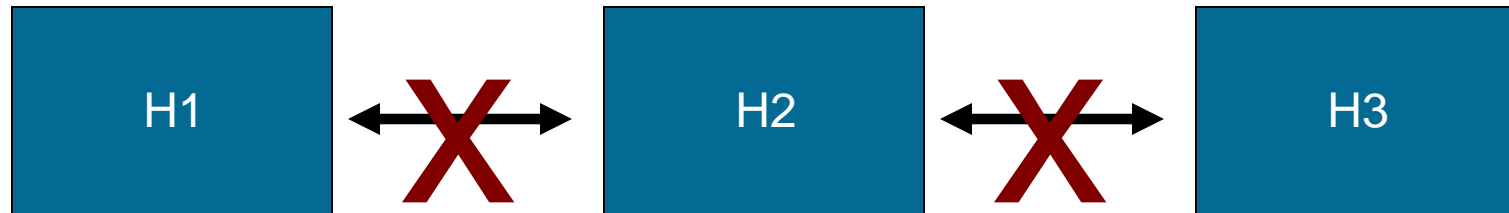
Excellent efforts, such as HL7, have not yet produced a robust clinical document model, and many of the standards are still underspecified

Vendors lock up data in proprietary formats



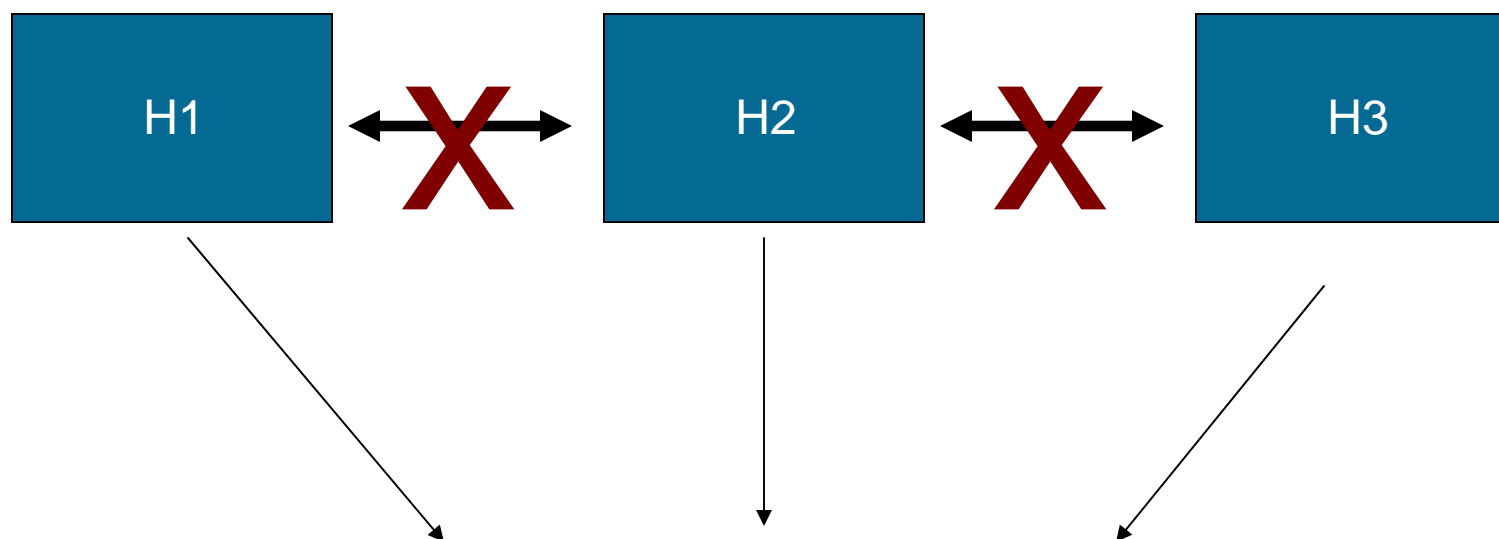
- Not motivated by Holy Grail
- Capture market share
- Lock in need for maintenance and upgrades
- Do not build in an “export” button

Hospitals do not share information



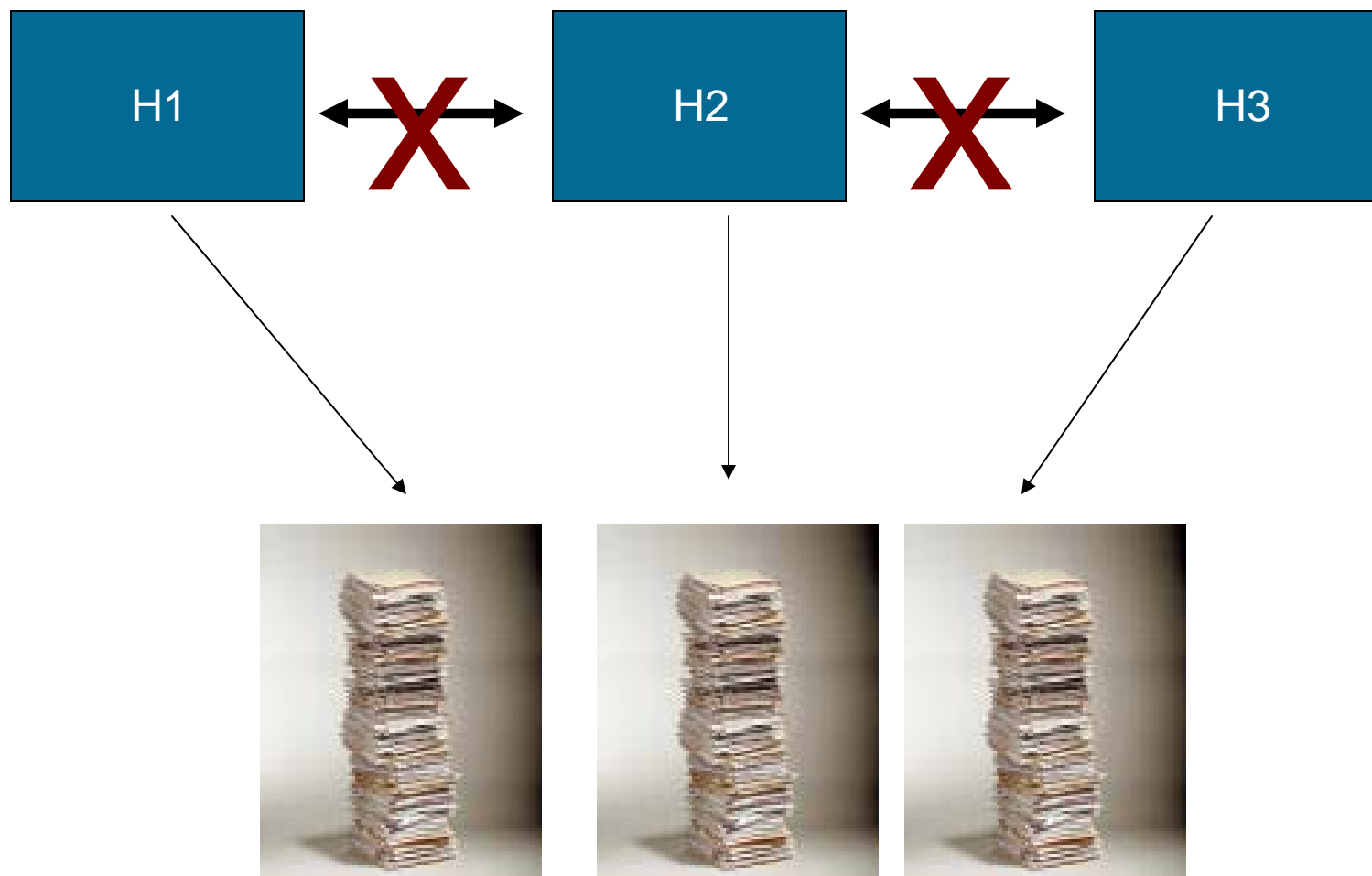
- Proprietary
- Perceived competition
- Citizen privacy
- Health Insurance Portability and Accountability Act
- No dedicated resources to do so

The citizen has rights to request the record



May I please have my record?

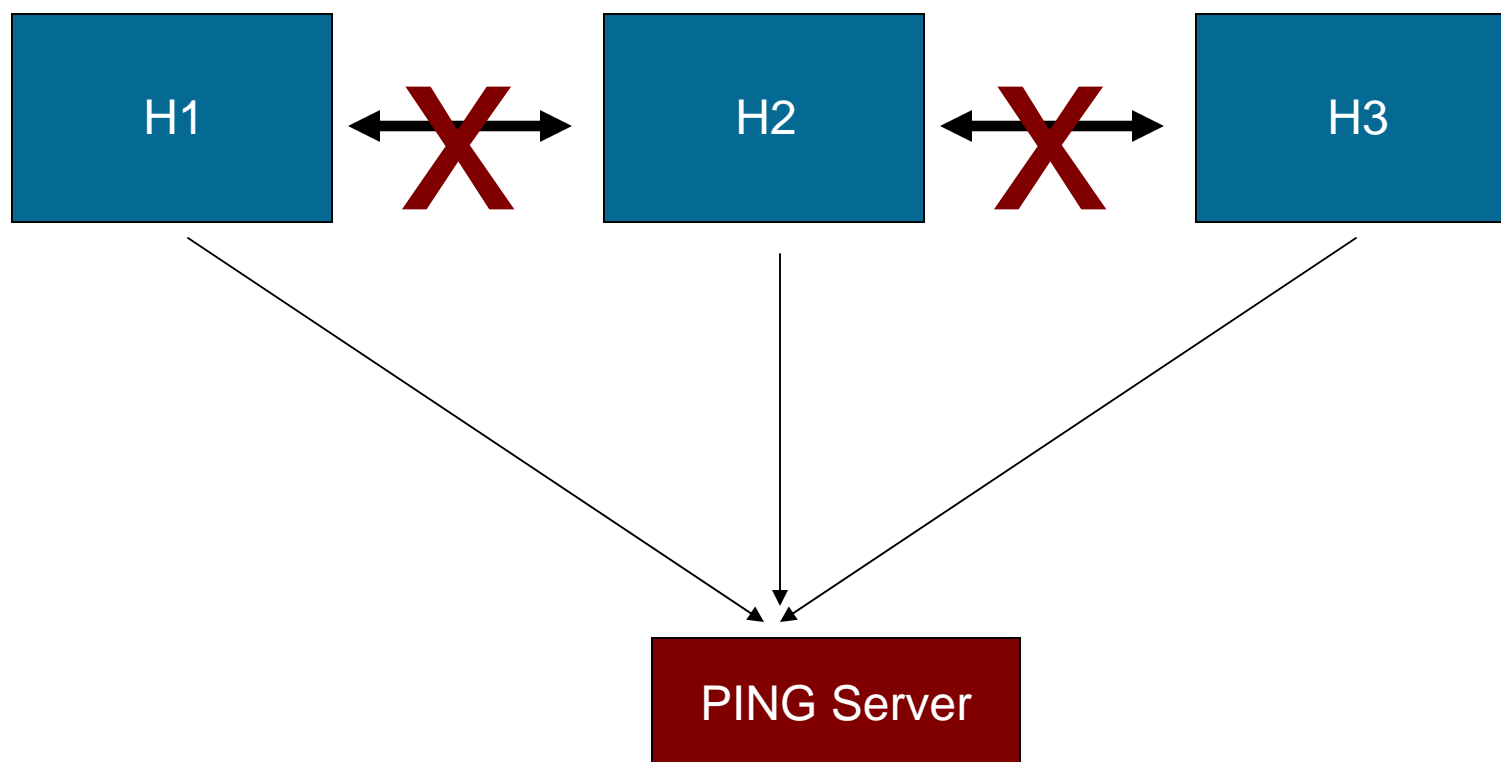
The answer is “yes” but . . .



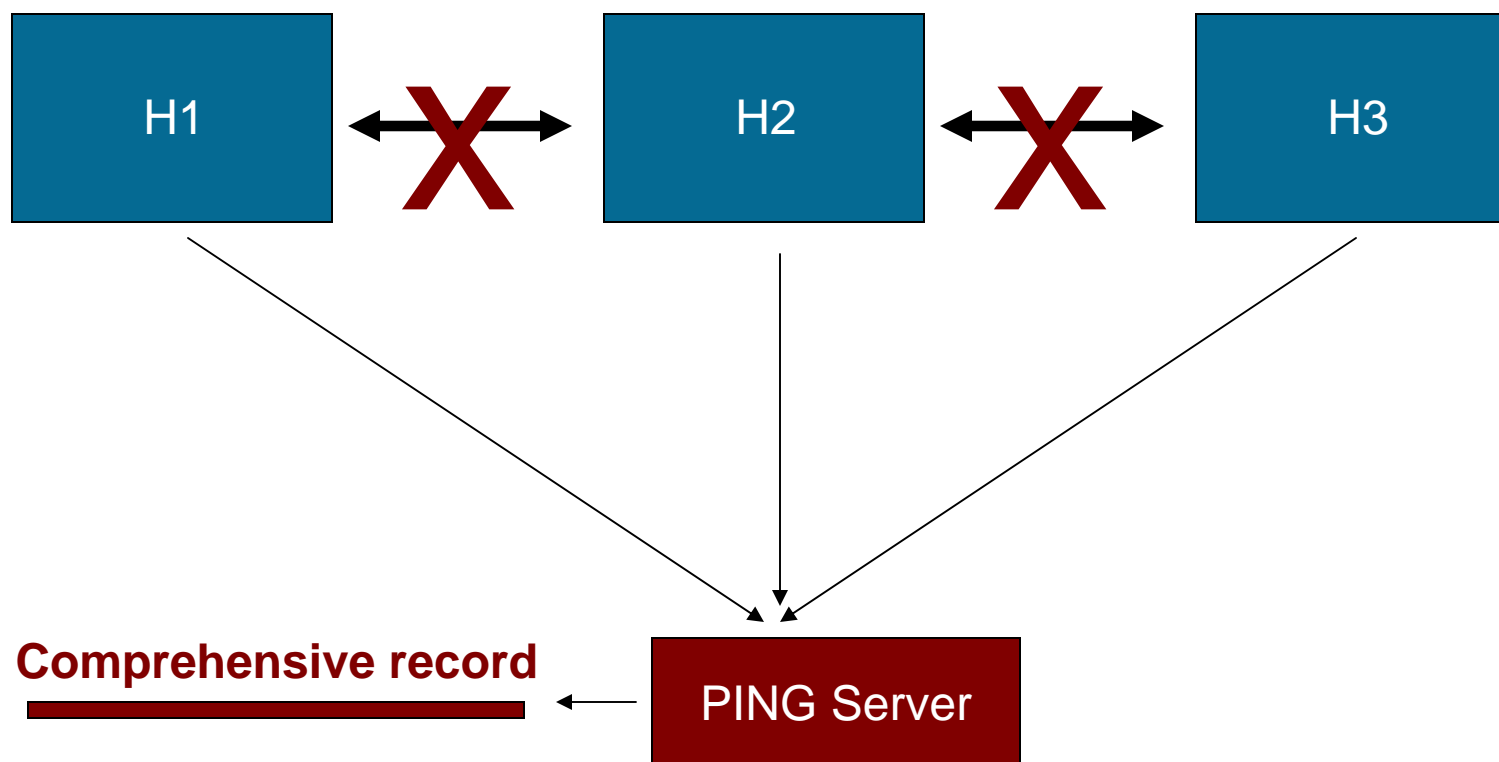
Current state of affairs

- Even when information is electronically available,
 - ✓ in an electronic health record
 - ✓ in a pharmacy management database
 - ✓ in a digital radiology systemthe citizen is generally given, at personal expense and inconvenience, a **hard copy**

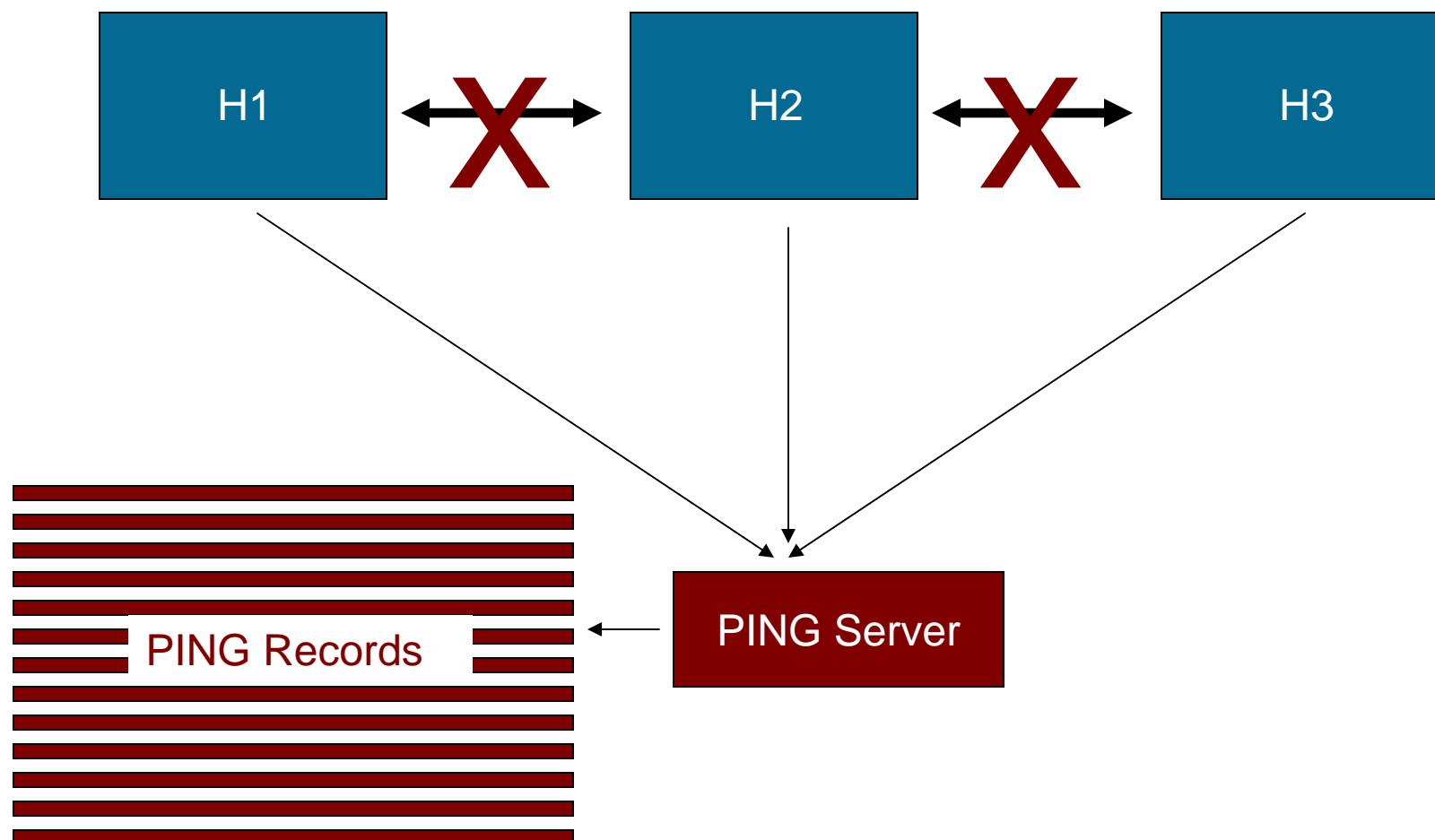
What if we gave citizens a tool to request their records electronically?



And create a personal health record



The collection of these records is the
population health database



Thesis

A variant of the EHR, the personally controlled health record, solves many of the problems, if implemented correctly, as a complement to the EHR



Clinical motivations

- So what if I had motivated you with a discussion of how this would be used in clinical care?
 - ✓ Incomplete information
 - ✓ Incomplete information
 - ✓ Incomplete information
 - ✓ Error checking
 - ✓ Decision support for doctors, citizens
 - ✓ Citizen/patient activation

Clinical justification

- Incomplete information leads to
 - ✓ Medical decision making with inadequate data
 - ✓ Increased testing
 - ☞ Increased cost
 - ☞ Decreased safety
- Is there incomplete information?
 - ✓ At a single institution 13.6% of primary care visits were missing information (JAMA 2005).

Quality and research justification

- Wouldn't it be nice if the reams of documentation produced during the course of medical care could be easily used to
 - ✓ measure outcomes and improve quality
 - ✓ Conduct research across sets of records



Children's Hospital
Informatics Program



Harvard
Medical School

Control is everything

- Careful, some talk about control but don't mean it
- The **personally controlled health record** is a distinct subset of the PHR

Not a personally controlled record

- Some hospitals in the US have begun to give citizens views of their electronic health record
- These are not instances of a personally controlled health record
 - ✓ not controlled by citizens
 - ✓ not cross-institutional

Boundaries

- A personally controlled health record may function well as part of a health portal or suite of tools
- The value added may promote adoption
- But not core PHR functionality:
 - ✓ MD-citizen e-mail
 - ✓ Scheduler
 - ✓ Decision support modules



PING

(Funded by the National Institutes of Health)

- next generation
- international
- ubiquitous
- personally-controlled
- longitudinal
- open source

Personally controlled health record

BMJ

- The keys to a successful personal health record are
 - ✓ personal control
 - ✓ Interoperability (HL7 RIM, etc)
 - ✓ open standards
 - ✓ rules to protect citizens

Information in practice

Public standards and patients' control: how to keep
electronic medical records accessible but

Kenneth D Mandl, Peter Szolovits, Isaac S Kohane

BMJ 2001;322:283-7

Citizen role

- Citizens can access the record
- Grant access to others
 - ✓ specific to their role
 - ✓ of selected portions of the record
- Store their record in a location of their choice
- Annotate in the record (but not delete)

What if citizen does not have Web access?

- Two images of PING/PHR
 - ✓ An intimate relationship between the citizen and the record
 - ☞ education
 - ☞ decision support
 - ☞ error checking
 - ☞ citizen annotation
 - ☞ the “Guardian Angel Vision”
 - ✓ A record controlled by, but rarely accessed by the citizen
 - ☞ controlled by the citizen
 - ☞ Used by the doctor, public health, researchers

What needs to be in a PHR?

- PHR is not a replacement for the EHR. It is a complement. But it may be more complete
- Don't need time a lab test was received in the lab
- Information required to provide clinicians a detailed clinical knowledge of the citizen's health picture
- Information required to run decision support and error checking for the citizen and the clinician
- Citizen entries

Open source code base

- The source code for PING is publicly available
 - ✓ A community of developers in Boston and a Canadian Governmental team are programming against it
 - ✓ A community of developers can build applications that run on top of it
- Participation in PING requires that the software not be modified to lose interoperability

PING

- The minimum set of requirements for storage and interoperability
- JAVA
- Each record is stored as an xml encrypted blob on a server of the citizen's choice
- Alternate back-end data stores are possible
- XML RPC like functionality for data exchange



Children's Hospital
Informatics Program



Harvard
Medical School

Original Investigations

Model Formulation ■

The PING Personally Controlled Electronic Medical Record System: Technical Architecture

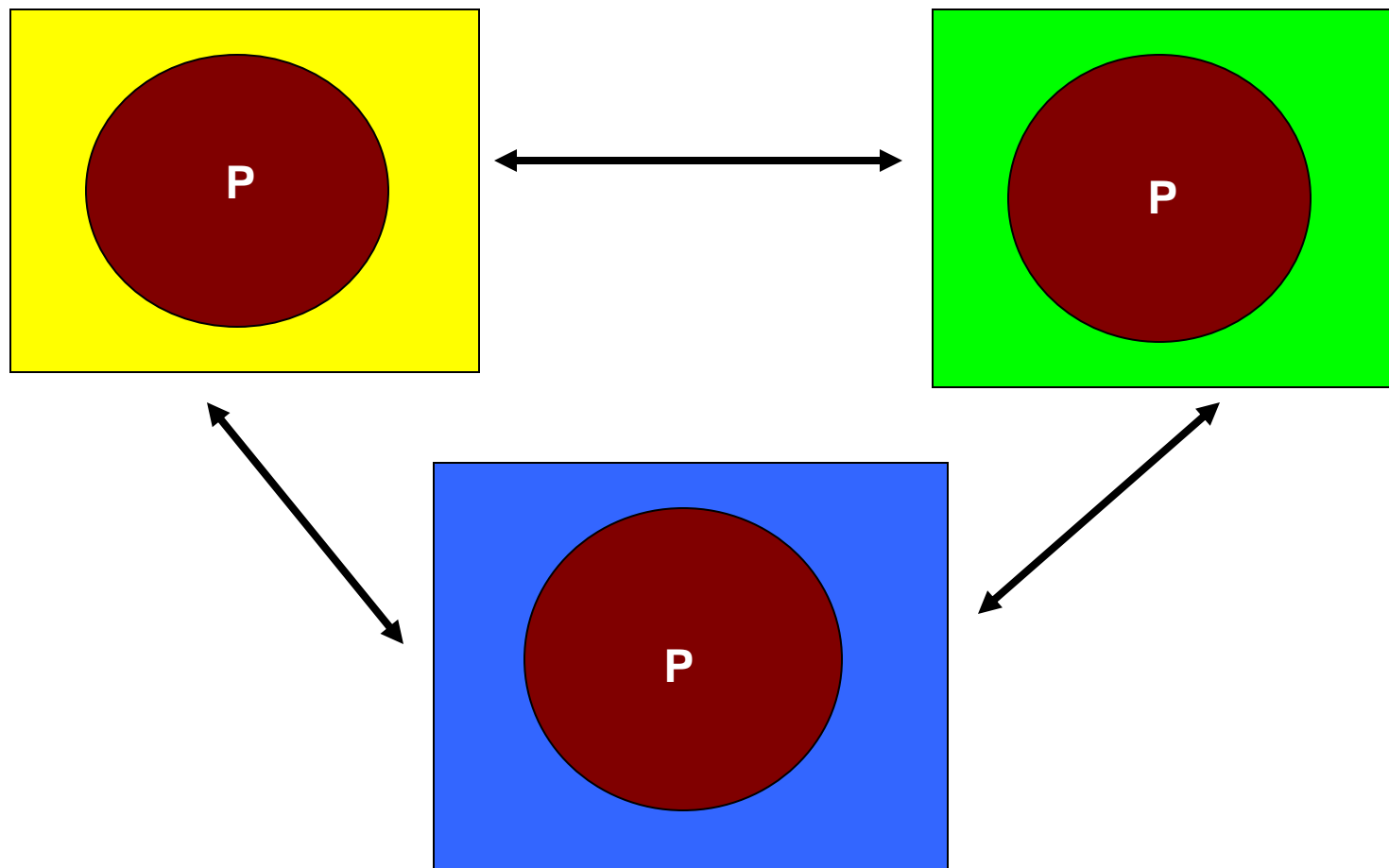
WILLIAM W. SIMONS, MS, KENNETH D. MANDL, MD, MPH, ISAAC S. KOHANE, MD, PhD

Abstract Despite progress in creating standardized clinical data models and interapplication protocols, the goal of creating a lifelong health care record remains mired in the pragmatics of interinstitutional competition, concerns about privacy and unnecessary disclosure, and the lack of a nationwide system for authenticating and authorizing access to medical information. The authors describe the architecture of a personally controlled health care record system, PING, that is not institutionally bound, is a free and open source, and meets the policy requirements that the authors have previously identified for health care delivery and population-wide research.

■ J Am Med Inform Assoc. 2005;12:47–54. DOI 10.1197/jamia.M1592.

PING

Stable core, variable bells & whistles, variable location





www.chip.org/research

- Guardian Angel Project www.ga.org (1994)
 - ✓ Record, Communication, Education, Decision support
- W3EMRS (1995)
 - ✓ Integration
- HealthConnect (1997) → → PatientSite
 - ✓ Communication
- PING I (1997-1998)
- PING II (1999-2003)
- Markle Foundation Technology Grant (2002)
- Connecting for Health PHR Working Group (2003)
- HHS NHII report (2004)
- PING III (2003-2006)
- CDC health promotion research (2004-2007)



Children's Hospital
Informatics Program



Harvard
Medical School

US National Health Information Infrastructure

- July 21, 2004—Sec'y of HHS released:
 - ✓ **The Decade of Health Information Technology:
Delivering Consumer-centric and Information-rich
Health Care: Framework for Strategic Action**
- This coincided with the new appointment of a
National Health Information Technology Coordinator,
Dr. David Brailer



Children's Hospital
Informatics Program



Harvard
Medical School

US Health and Human Services Framework

- Goal 1: Inform clinical practice
- Goal 2: interconnect clinicians
- Goal 3: personalize care
 - ✓ *Strategy 1. Encourage use of Personal Health Records*

So why not just use EHRs

- Pluses

- ✓ Will become more common over next five years
- ✓ Possible dominance by a few vendors
- ✓ NHII initiative may help make the data available

- Minuses

- ✓ Inter-institutional politics not likely to change substantially
- ✓ Nationwide monolithic EHR system unlikely
- ✓ Privacy issues complex
- ✓ No mechanism to feed back to citizens

To be clear

- The PHR *needs* the EHR
 - ✓ Need electronic information
- In Massachusetts, Blue Cross Blue Shield is investing \$50M US in EHR adoption (\$1B coming)

Challenges: adoption

- Chicken and egg problem
- Activation energy
- Consumer drive
- Technology diffusion

CDC Health Protection Research Study

1. Citizens as sentinels

- ✓ To augment the conventional surveillance data sources with personal health record data

2. Personally controlled record as personal advisor

- ✓ To develop a system for delivering tailored, targeted health messages to citizens, with content and tempo modulated by real time surveillance

3. Evaluation

- ✓ To measure the impact of tailored health messages, linked to surveillance, and delivered through a personal health record



Children's Hospital
Informatics Program



Harvard
Medical School

Two-way information flow

- Opportunity to
 - ✓ collect data from citizens/employees
 - ✓ deliver messages to citizens/employees

Public health challenges

- Consent process?
 - ✓ For mandated reporting?
 - ✓ Aggregated data?
 - ✓ “De-identified” data?
 - ✓ Identified data?
- By allowing citizens to opt out, even of studies that use de-identified data, are we creating bias in our research and public health investigations?
 - ✓ Yes
 - ✓ Alternative :Bias at an earlier stage—nonparticipation in PING because no guarantees of control

Domain: Influenza prediction and control

- Link PING to AEGIS
- Develop health messages around influenza prevention and control that change in content and tempo with prevailing conditions
- Give PING to US employees, Canadian citizens (seeking care at AHSC)
- Analyze impact on knowledge, attitudes, beliefs, behaviors, **immunization rates**

So what did we need to build?

- Survey tool
- Poller
- Messaging tool
- Decision engine



Take home message

- Citizens/employees need to have complete information (across location and time) for safe, effective care
- With EHR adoption, finally have the electronic data
- Can leverage the citizen's right to access, to create integrated record
- To encourage participation, and gain trust, must ensure complete citizen control
- To ensure interoperability, must create a light- weight set of standard protocols for transfer and storage of medical information
- Additional functionality may be proprietary, but must NOT break the interoperability



“Whoa—way too much information!”



Children's Hospital
Informatics Program



Harvard
Medical School

